

Newborn Screening Update

Michigan Newborn Screening Program

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Introducing

If you have had a reason to call the Newborn Screening Laboratory, chances are you talked to Harry Hawkins. As laboratory manager for the past eight years, Harry feels that he has talked to people from all birthing facilities across the state.

All of his twenty-eight years in laboratories have been with Newborn Screening except for several months at the U.P. facility in Powers long before it was closed. Harry helped start the hypothyroidism screening test in 1977. He has seen the program grow from just "PKU" testing to its current level of eleven disorders. It isn't just PKU testing anymore and Harry takes every opportunity to let people know. Tandem mass spectrometry has really expanded the number of disorders that can be screened and Michigan program is expected to grow in the future.

Harry is especially proud of the laboratory staff and the quality of high volume work reported out from so many specimens. The implementation of the new information system software has been a big project that affected everyone in the laboratory.

Still a Yooper at heart, Harry grew up in northern Michigan and went to college at Lake Superior State in Sault Ste. Marie. He likes running, hunting, and playing the trumpet.

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Why is it recommended to maintain a NBS log?

As hospitals have been visited over the past 6 months, the maintenance of a NBS log has been addressed. Why is a NBS log recommended? Well, first we have to look at what is necessary to record in the NBS log. The following information is essential: the baby's name, date and time of birth, birth weight, date and time the NBS specimen was obtained. It is also helpful to include the date the NBS specimen is sent to the State laboratory, NICU, TPN, and RBC transfusion information. The name or initials of the person obtaining the NBS specimen may also be included. Maintaining a NBS log will save staff time both at the hospital and at the NBS program. Keep in mind, that it is important to ensure that the NBS log is kept current as missing information is the same as no information.

Here are two examples to explain how important this can be. The first example was the State laboratory's receipt of a NBS screening card without blood. When the hospital was contacted, they were able to utilize their NBS log to quickly identify the infant and make a determination of why there was no blood on the card. This took a minimal amount of time including one phone contact with the hospital and one return phone call to NBS program. The second example was the State laboratory's receipt of a NBS screening card without the date, time, or initials of the person obtaining the specimen. When the hospital was contacted they were not able to verify that the NBS specimen was obtained between 24 and 36 hours of age. The documentation in the infant's medical record did not indicate when the NBS specimen was obtained just "NBS done." They noted that they did not maintain a NBS log.

It is extremely important to verify that the information on the NBS screening card is complete and accurate prior to mailing the specimen to the State laboratory. It is also very important for the medical record to contain complete documentation that the NBS was obtained. However, in those instances where information is missing, contacting a hospital where a NBS log is kept current can reduce the time it takes to obtain the missing information and may prevent the infant having to be re-screened.

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A Few Reminders ...

DOCUMENT THE INFANT'S BIRTH WEIGHT IN GRAMS

It is important to document the infant's weight in grams on the NBS specimen card. The state lab requests that you please only use grams as that is the measure that the computer software recognizes.

MARK BOTH HERITAGE AND RACE ON THE NBS SPECIMEN CARD

It is important to mark both the heritage (Hispanic or Non-Hispanic) and the race of the infant on the NBS specimen card. This information is necessary to aid in the determination of accurate screening results.

MARK THE BOXES RELATED TO NICU/SCN, RBC TRANSFUSION, AND TPN

Whether or not your hospital has a NICU or SCN, it is important to mark the boxes indicating whether or not the infant was in a NICU/SCN or received TPN or a RBC transfusion (include dates of transfusion).

DO NOT APPLY TAPE OR STICKERS TO THE NBS CARD

The lab has requested that you not apply tape or stickers to the NBS card. This creates a problem when the lab is separating the different sections of the NBS card. Thanks in advance for your cooperation with this request.

POLICY AND PROCEDURE

Does your hospital have a policy/procedure for NBS? If so, now may be a good time to review it to ensure that the information is up to date. If not, now may be a good time to develop one. Contact Midge McCaustland, RNC, MSN if you would like assistance in the development of a policy/procedure for NBS.

OBTAIN THE NBS SPECIMEN PRIOR TO TRANSFERRING THE INFANT

If the infant is going to be transferred to a tertiary center, it is important to obtain the NBS specimen prior to the transfer. The provider caring for the infant at the time of birth is legally responsible to ensure that the NBS specimen is obtained.

WHEN THE INFANT IS BEING PLACED FOR ADOPTION, ETC.

If the infant is being placed for adoption or is a "safe haven" baby, the name of the person or agency that has the responsibility for authorizing care and treatment of the infant may be documented on the NBS card in the space where the mother's name and demographic information is requested. The name and demographic information of the adoptive parents may also be entered if this information is known.

If there is knowledge that the last name of the infant on the birth certificate is different from the last name of the mother, it is helpful to document the infant's correct name on the NBS specimen card.

NBS BROCHURE

Check your supply stock to ensure that you have the most current copy of the NBS brochure, entitled "A First Step to Your Baby's Health." The brochure can be ordered, free of charge, by contacting Valerie Klasko at 517-241-5583.

NEWBORN SCREENING EDUCATION

Midge McCaustland, RNC, MSN, is available to provide a variety of educational materials and presentations. She is available for one-on-one consultation and group presentations. If you would like her to speak to your staff or at your conference, call her at 517-335-8588 or send her an e-mail to mccaustlandm@michigan.gov.

NEWBORN SCREENING EDUCATION PROGRAM

You may access the NBS Online Tutorial two ways: 1) go directly to the site at www.training.mihealth.org or 2) go to the NBS website at www.michigan.gov/newbornscreening.

FOLLOW-UP LETTERS

Hospitals that have been visited by the nurse educator earlier this year will receive a follow-up letter with the request to complete and return a short questionnaire. Feel free to contact Midge McCaustland, RNC, MSN at 517-335-8588 if you have any questions.

A Father's Story ...

Ryan was delivered at term by Cesarean Section. He weighed over 9 pounds. He presented with breathing irregularities and subsequent low pulse ox level in the nursery. He was admitted to the NICU and the first course of treatment was c-pap with little improvement. About an hour later they decided to intubate to facilitate the administration of, I think, Serventa even though he was full term (I guess the x-ray showed "something"). I think he was extubated within about 6 hours with significant improvement in respiratory function. They did not really know what was going on at that point but he was doing better and started feeding by bottle. Between the morning of the 2nd day and the morning of the 4th day he became progressively more lethargic, having to be tube fed. When he was 4 days old his digestive system was significantly backed up when the feeding tube was inserted and drawn on. An immediate x-ray revealed something, and follow-up x-ray confirmed Necrotizing Enterocolitis (NEC), despite being full term and good weight with no apparent cause (he was the oldest, largest baby the 60-something surgeon had ever worked on for NEC). He had emergency gut surgery that afternoon and wore an ostomy bag for about 2 months thereafter. He had follow-up surgery to remove more damaged small and large intestine and has been healthy gastrointestinal-wise ever since.

The same day as the surgery the newborn screening results identified the hypothyroidism. He was immediately started Synthroid which he will likely be taking for life. His treatment history indicates that he may not have a thyroid or has a weird form of central hypothyroidism.

Anyway, given the complications, his condition would probably have been diagnosed without the newborn screening given the long hospital stay to recover from surgery and the lethargy that would have persisted. However, that would have resulted in a delay in treatment.

Submitted by Ryan's dad, David.

Information Sharing ...

Hospitals or other providers are invited to share information on their practices, policies, procedures, and experiences in an effort to improve the NBS process. This information is not to be considered a "requirement" of the NBS program. It is merely a "sharing of ideas" that you may choose to evaluate for use in your facility. The bottom of this page contains a process submitted by Garden City Hospital. It was helpful in meeting their goal of reducing the number of late NBS specimens.

If you would like to contribute an idea to share, please e-mail the information with a contact name, phone number, and permission to include the information in the NBS Update to mccaustlandm@michigan.gov.

Ideas to share ...

The Birthing Center at Garden City Hospital utilizes pre-metered envelopes for use when the mailroom is closed. The hospital mailroom is open Monday through Friday, closed weekends and holidays. In order to better service our patients, the nursing staff researched the use of pre-metered envelopes. As part of our Newborn Screen procedure, we know that the Newborn Screens must be in the mailroom by 1400 on Friday, as they are sent out by 1430. After that time we put the screens in an envelope pre-metered for \$1.06 (this will hold up to 5 completed cards). This envelope can be placed in the mailbox outside of the front entrance of the hospital by 1300 on Saturday for pick-up by 1330. Any additional specimens after this time will be taken to the hospital mailroom by 0830 Monday morning, as the mail is sent out at that time. No screens will be placed in the outside mailbox on Sunday or holidays, because it will not be picked up until 1330 (it is picked up at 0830 in the hospital mailroom). The staff nurses have taken "late specimens" very seriously, and the use of pre-metered envelopes has helped to assure timely mailings.

Submitted by Janelle Cochran, Garden City Hospital

We are in the process of updating our mailing list. Please *complete the information below* for additions, corrections or deletions and *return this page* to the address listed below. You may also send an e-mail with name or address changes to:

HowardA@michigan.gov

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A blue oval containing the text "Michigan Newborn Screening Program" in white.

Michigan Newborn Screening
Program